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“Ordinary people only”: knowledge, representativeness, and the publics of public participation in healthcare

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Public involvement in healthcare is a prominent policy in countries across the economically developed world. A growing body of academic literature has focused on public participation, often presenting dichotomies between good and bad practice: between initiatives that offer empowerment and those constrained by consumerism, or between those which rely for recruitment on self-selecting members of the public, and those including a more broad-based, statistically representative group. In this paper I discuss the apparent tensions between differing rationales for participation, relating recent discussions about the nature of representation in public involvement to parallel writings about the contribution of laypeople's expertise and experience. In the academic literature, there is, I suggest, a thin line between democratic justifications for involvement, suggesting a representative role for involved publics, and technocratic ideas about the potential 'expert' contributions of particular subgroups of the public. Analysing recent policy documents on participation in healthcare in England, I seek moreover to show how contemporary policy transcends both categories, demanding complex roles of involved publics which invoke various qualities seen as important in governing the interface between state and society. I relate this to social-theoretical perspectives on the relationship between governmental authority and citizens in late-modern society.

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Introduction

The involvement of the public, as citizens and clients, in the management and provision of public services is an aim now common to governments across much of the economically developed world (e.g. Hiller *et al.* 1997, Vigoda 2002, Reddel and Woolcock 2004), and across the political spectrum. Various reasons for the current vogue for participatory and deliberative methods of engagement by the state with its publics have been suggested (Abelson *et al.* 2003), including the need for greater direct public accountability, the perceived 'democratic deficit' between electoral processes and the implementation of policies by state administrators, and perhaps above all, the emergence of a more sophisticated and demanding citizenry as premised in recent theoretical accounts of contemporary Western society (Beck 1991, Giddens 1991). In the United Kingdom, public participation has been central to two otherwise divergent aims of the Labour governments elected since 1997: 'democratic renewal', with its aim of rejuvenating the connection between public and state, and the 'modernisation' of the welfare state to render it more appropriate to the purportedly changed complexion of society (Gustafsson and Driver 2005).

In healthcare, public and service-user involvement has generated much empirical analysis

(Crawford *et al.* 2003), and a growing amount of theoretical consideration. Research has identified various failings of the operation of participation in practice, from the selectivity with which the involved 'public' is chosen (e.g. Gollust *et al.* 2005), through the way power operates in participation processes to prioritise some discourses and marginalise others (e.g. Hodge 2005), to the use of public-involvement initiatives by managers as a tool of self-legitimation or a means of ratifying *faits accomplis* (e.g. Harrison and Mort 1998). A sustained angle of attack has been on consumerist models, which in the UK explicitly informed the way public involvement was deployed alongside the internal market in health and social care in the 1990s, and which are seen to continue to pervade participation practices since 1997 too. The individualising tendencies which this form of public involvement is seen to embody are often contrasted with forms which emphasise empowerment, and hand over a degree of control rather than merely consulting the public to improve responsiveness (Cook 2002). Parallel to this argument, there is a concern in the literature for the tendency towards selectivity and elitism in public-involvement practice, with a reliance on self-selection or the selection of acquiescent or financially better-off individuals that results in only a few voices being heard, usually at the expense of socially marginal groups (Church *et al.* 2002).

Together, these two concerns suggest a democratic failure of public-involvement initiatives. In neglecting to engage with large swathes of the public, and in using involvement as a means of consultation on a few narrow, predetermined areas of policy, public participation is seen to fall short of its promise to provide a direct, more-than-tokenistic, say in the governance of health to the public. However, another justification for participation, the technocratically beneficial input that may derive from the knowledge and experience of the public, does not rely in the same way on the breadth of participation demanded by democratic rationales: indeed, following recent arguments in the field of science studies, it may even call for a narrowing of the public involved, on the basis not of democracy but of expertise (Collins and Evans 2002). A tension emerges between public involvement premised on broad-based representation of an entire public (whether 'citizens', 'potential patients', 'local community' or 'users of a service') and one which draws on the knowledge of a select few within it.

In this paper I explore this tension between technocratic and democratic rationales for public involvement. Considering recent writings on the nature of representation in public involvement and about the kinds of contributions made to healthcare delivery by those held up as examples of 'lay experts', I argue that there are actually considerable overlaps between the two and the inputs they provide. Representational accuracy does not necessarily rest on faithful reproduction of the social profile of the wider population within the involved group; the input of 'lay experts' is not limited to a narrowly technocratic contribution to the scientific or managerial aspects of service delivery. The qualities required of involved members of the public are not limited to 'representativeness' or 'expertise', but rather encompass various attributes seen as important in governing the interface between state and society. Furthermore, contemporary policy, I argue, actively blurs notions of expertise and representativeness, a trait which I seek to demonstrate with reference to recent attempts in Britain to promote 'Patient and Public Involvement in Health', and relate to recent commentary on the nature of the relationship between the state and the individual in contemporary Western societies.

Representation, democracy, and their others

Despite acknowledging the various rationales for public participation beyond the extension and fulfilment of democracy, much of the literature on the matter focuses on the question of the representativeness of initiatives, offering criticism of their frequent failure to reflect the characteristics of wider society in the groups used. As Crawford *et al.* (2003: 46) note in their review of 1108 papers on involvement in change in health services, "statements about representativeness are very common in the literature but the meaning of the term is rarely considered." Church *et al.* (2002: 17) echo much of the literature when they bemoan the reliance

of Canadian policymakers on “the same traditional middle-class cross-section of citizenry to represent the interests of all”; similar points are made in various national contexts by others (e.g. Macdonald 2003, Contandriopoulos 2004, Gollust *et al.* 2005). Through a combination of self-selection by those wishing to be involved and selection of the ‘right’ kind of people by those managing the process, public-participation initiatives are seen to represent some subgroups of the public better than others.

Two proposed solutions to the legitimacy problems that arise from such scenarios are random selection, to provide a statistically representative sample of the target population, and election. These approaches are costly and administratively complex; moreover, as various writers point out (Parkinson 2003; Bourdieu 1991), they do not guarantee more ‘accurate’ representation in the first place. There is no fundamental reason why the descriptive representation of shared characteristics, such as ethnicity or class, promised by random selection should translate into accurate representation on the level of expressed opinions. Efforts to ensure inclusion of groups defined by particular demographic characteristics prioritise these assumed bonds over other, less socially prominent, boundaries of commonality and difference, with potentially insidious effects. On this basis, certain proponents of deliberative democracy suggest quasi-electoral models of representation over approaches such as citizens’ juries which involve random selection (Parkinson 2003). Yet electorally mandated relationships do not guarantee ‘accurate’ representation either (Bourdieu 1991), especially where (as with deliberative democracy) negotiation and transformation is required of those involved (Abelson *et al.* 2003).

Some deliberative democrats argue that it is not representation of individuals that is important, but representation of the range of discursive positions within society (Dryzek 2001). Various writers on public participation similarly seek to circumvent this difficulty by advocating ‘experiential representation’ (Prior *et al.* 1995, Frankish *et al.* 2002). Rather than via formal procedural mechanisms, the argument here is that “[experiential] representation, based on shared experiences where needs are actively and subjectively assessed, enhances the legitimacy of representation when economy of time and problems of scale restrict participation” (Frankish *et al.* 2002: 1476). In this conception, representation becomes a matter of common experience in the situation of the group represented. Socially defined signifiers of commonality cannot be assumed relevant: instead an active, dialogical connection, along with personal experience, is crucial to representational authenticity.

Whilst this notion of representation may have its place in refining the electoral mechanisms of liberal democracy, it also points towards other forms of contact between the state and its publics. Rather than addressing the unitary ‘the people’ of liberal democracy, particular groups are to be involved in their particularity—of situation, experience or identity. This suggests a rationale for participation beyond ‘democracy’ in the narrow sense, premised instead on an understanding of the views of particular groups: the kinds of role suggested by Lomas (1997) for ‘the public as patients’, who might provide experiential input into resource-allocation decisions alongside the input of ‘the public as citizens’, with their more narrowly democratic task of ensuring correspondence of decisions to the (general) public’s wishes.¹ However, these roles are not discrete. Even in discussing this priority-setting function of ‘the public as citizens’, people emphasise the “practical knowledge and personal experiences” that participants can offer (Litva *et al.* 2002: 1834). The task of *democratically* representing the citizenry’s collective views through participation is enriched by an experiential component which sensitises the representative to the

1 It is worth noting that in the UK, both in large-scale democracy and in democratically oriented forms of public participation, ‘the public as citizens’ is usually a small subset of citizens (the voting or participating public) who speak for citizens and certain non-citizens alike (for example those who either do not possess UK citizenship or do not exercise it but who are nevertheless entitled to certain services: e.g. citizens of other European Union member states).

patient's perspective.²

On this basis, narrowly democratic ideals of (electoral, or descriptive-statistical) representation are not the only defensible rationale for public involvement—even in questions of democratic control over resource allocation, and all the more so in wider questions not directly concerned with distributing finite resources. Certain qualities beyond mere 'representational licence' may, it seems, legitimately come into play in public participation.

'Lay expertise'

Alongside this recognition of the value of qualities such as experience, affectedness and understanding, academics and policymakers have come to embrace the idea of the public as an important source of technocratic input to health management and provision, as witnessed in various government initiatives (e.g. Department of Health 2001) and in the surge in the use of terms such as 'lay knowledge', 'lay expertise' and even 'lay epidemiology' in academic writings (Prior 2003). In the field of science studies, where the authority of non-scientific understandings has long been recognised (and, for some, overstated), recent attention has focused on how to distinguish lay contributions to scientific knowledge which are valid and useful from those which are not. Collins and Evans (2002) offer a normative framework of who 'should' be involved in scientific endeavour, developing a distinction not between scientists and laypeople, but between those possessing and not possessing relevant 'expertise', whether certified through the qualifications and regalia of a given field of esoteric science, or uncertified and derived from experience. Theirs, then, is not a framework for the democratisation of science, but for the extension of contributory rights on an explicitly technocratic basis.

Exactly what constitutes 'expertise' in Collins and Evans' (2002) outline, however, is not entirely clear-cut. One of the examples on which their argument rests is Epstein's (1996) study of the contribution of AIDS activists to the conduct of antiretroviral-drug trials. These individuals accumulated vast knowledge about the virus, the drugs and trial methodology to become scientifically conversant and gain such credibility that clinicians felt obliged to recognise their expertise according to medicine's own standards. However, scientific expertise was not itself what activists brought to the table in Epstein's account. They contributed an understanding of human values, articulating the need for a trade-off between 'absolute scientific integrity', with its promise of sound medicine for future generations, and scientific pragmatism to help palliate suffering in the present. What was crucial was their ability to gel their axiological concerns with scientific arguments, for example around the desirability of recruiting diverse groups to trials to improve external validity of findings, in opposition to those who preferred the scientific 'purity' delivered by stricter eligibility criteria. Fundamentally, their contribution was ethical rather than scientific—but expertly aligned with existing sides of scientific and methodological debate.

In these terms, there may be a thin line between *expertise* and the kinds of *sensitising experiential contributions* of particular, affected groups outlined in the previous section. The distinctiveness of the contribution of the 'uncertified experts' identified in Collins and Evans' schema thus comes under assault from two very different epistemological positions. For the more constructivist wing of science studies, any separation of technical and political questions is unviable, as the very idea of a 'purely scientific question', unadulterated by wider social considerations, is attached umbilically to the licence of the powerful to define and delimit what science is (Wynne 2003; cf. Irwin 2004). For those who accept the epistemic superiority of scientific over non-scientific understandings of the world, meanwhile, the idea that 'lay experts' have a distinctive and worthwhile contribution to make is doubtful, at least in healthcare. Prior

2 Of course, part of the argument for the effectiveness of democracy as a political system rests on its ability to draw on the knowledge of 'the people', including their personal experiences, but there is nevertheless a shift here in the idea of the public as the source of collective will and the idea of the public as a source of relevant personal experience.

(2003: 53) argues that patients' expertise in their own illnesses is seldom qualification for involvement in questions of medical science or health-service provision:

They often have detailed knowledge of other people as well as of themselves, ... and intimate knowledge about the circumstances in which they live. ... And all in all, they are experts by virtue of 'having experience'. Yet, experience on its own is rarely sufficient to understand the technical complexities of disease causation, its consequences or its management. This is partly because experiential knowledge is invariably limited, and idiosyncratic.

For Prior, a disingenuously technocratic rationale for public participation should not substitute for the inclusion of the public on a democratically representative basis—"the worthy political aim of ensuring participation and consultation of the lay public in all matters to do with medicine" (Prior 2003: 54).

Yet there seems to be more to lay knowledge of medicine and health-service delivery than the merely "limited, and idiosyncratic" experiential knowledge that Prior describes. Lambert and Rose (1996) explore the nuanced, sophisticated understandings of patients with a genetic predisposition to high cholesterol, finding an embodied insight distinct from clinical apprehensions of the condition. These patients competently assessed and assimilated "a deluge of often contradictory information from a multiplicity of sources, laden with different levels of prestige and trustworthiness" (Lambert and Rose 1996: 69). Their accounts contained scientific inaccuracies (albeit frequently imparted by their doctors), but also incorporated an "understanding of the historically contingent and partial nature of scientific knowledge" (Lambert and Rose 1996: 73). Similarly, Nettleton and Burrows (2003: 171) describe information available on the internet as used by patients as "a reflexive resource that demands proactive engagement in order to obtain strategic advantage in the real world." Ziebland (2004) discusses narratives of patients drawing on internet resources to gain knowledge about their treatment, preparing themselves for encounters with family physicians whose knowledge of specialist medicine was inevitably limited.

Common to these analyses (Lambert and Rose 1996, Nettleton and Burrows 2003, Ziebland 2004), and to that of Epstein (1996), are accounts of how the experience of disease prompts a desire to acquire detailed knowledge of aetiology, prognosis and entitlement to service provision. The knowledge obtained is both clinical and social, but does not conform to accounts stressing the centrality of the clinician as sole source of expertise. What these accounts point towards is how the reality or risk of disease may bring out a willingness and ability to become expert in ways which combine experiential dimensions with conventional scientific knowledge to develop a new, positioned perspective on the science or delivery of medicine. In the process, individual and collective concerns become meshed: Epstein's patients took the role of advocates and activists; Ziebland (2004: 1788) similarly explores the collectivist dimensions of her respondents' knowledge, describing, for example, how, "after what [a patient with inflammatory breast cancer] described as her 'blackest day', she decided to set up a website and a brochure."

Democracy, expertise and the 'active citizen'

This capacity to bind knowledge of managerial or scientific practice with an experiential sensibility to the concerns of the public represents an intriguing kind of expertise, encompassing the technical detail of medical science and provision and the perspective of the individual patient. Considered in relation to the idea of 'experiential representation' detailed above, it hints at a form of participation that might bridge the divide, apparent in the literature, between public involvement premised on democratisation and more technocratic rationales. However, this capacity seems associated with certain other social characteristics. Epstein's (1996) AIDS activists were the mobilised, middle-class mouthpiece who took it upon themselves to speak for their community of patients; Ziebland (2004) stresses how social identity was crucial in both her interviewees' search for knowledge and their ability to deploy it to their advantage; Nettleton and

Burrows (2003) are explicit in arguing that the utility of internet information rests on the reflexive capacities of users to interpret, discern and marshal it to their gain. Is an argument for the role of particular individuals, who combine democratic and technocratic concerns through the qualities of reflexivity, motivation, communicative ability and so on, essentially an argument for the participation of a select few to mediate between state and society?

Such an argument has elitist overtones, but it also echoes the case advanced by some deliberative democrats for 'discursive democracy' (Dryzek 2001). Others have discussed the potentially democratising effects of the process of public participation itself, through which motives may change from self-interested to collectively spirited (Simmons and Birchall 2005), identities may be transformed (Davies and Burgess 2004) and those not present may empathetically be given voice (Barnes *et al.* 2004a). As Barnes *et al.* (2004b: 273) point out, such effects may signal how

a politics of presence (rather than being the antithesis of the politics of representative democracy) is articulated with [representative democracy] in new discursive constructions.

Tensions remain, however, between the (narrow-) democratic notion of statistical-descriptive representation of 'the public as citizens' and what Barnes *et al.* (2004b: 269) call the "'new' [institutional] norms of deliberation and involvement" (cf. Milewa 2004). This is especially the case in domains of policy which are expected to be democratically determined, such as resource allocation. Indeed, it is possible to argue that the contribution of, say, Epstein's AIDS activists to clinical-trial methodology represented the *improper*, undemocratic influence of a well organised pressure group on priorities which should be set through democratic processes involving 'the public as citizens' (though which had of course in practice been influenced more by the knowledge and norms of the technical elite of clinicians which controlled them). Is the motivation and capability for involvement and putting forward the views of a/the public—the "conscious and thought-out desire to be, or to become, a certain type of person" (Campbell 2005: 689)—something which enhances or impairs the representational connection, and the effectiveness and worth of the contribution that public participation makes?

This is an empirical question; undoubtedly there are potentials and dangers inherent in such approaches to the involvement of the public in healthcare governance. Regardless of such judgements, though, what is certain is that these kinds of approaches to the interface between the state and its publics are increasingly prevalent in contemporary Western societies, in health and other fields. As various authors illustrate, late-modern social policy—especially, in Britain, the social-policy reforms of post-1997 Labour governments—is constructed around the view that society has fundamentally changed, that it is composed of increasingly reflexive and decreasingly deferential citizens, and that this requires a modernisation of the welfare state (including its governance and modes of interaction with the public). Moreover, this modernisation expects and relies upon the agency of these presumed 'active citizens': their reflexivity, their rational action, their acquiescence.

There are negative consequences for those who do not fit this active-citizen mould (Ellison 1997). The state, meanwhile, depends on the collaboration of mediating individuals or groups to ensure that its provision meets as effectively as possible the exigencies of this diverse society. Green (2005) explores one such form of mediation, the way in which policymakers involve certain individuals on the basis not of their representative mandate or expert knowledge, but of their 'typicality' of the 'hard-to-reach communities' that social-policy interventions are designed to affect. Schofield (2002) offers another example, of the way in which communities are involved in urban-regeneration initiatives as a source of local knowledge, capacity and agency which is expected to ensure the appropriateness of the state's intervention. Public involvement in health can be viewed in a similar light, as a means of assisting the effectiveness of welfare-state provision not by drawing on democratic legitimacy, nor necessarily on the expertise, narrowly defined, of the lay public, but through enlisting the agency of certain groups whose capabilities

give them a special mediating function. These might be, from an optimistic or pessimistic perspective, either the 'active citizens' or the 'reflexivity winners' (Ellison 1997) of a contemporary society where citizenship is a multiplicitous status applied differentially across the population (see Clarke 2005).

Whether positive or negative, though, what should be clear from this overview is that analyses of public participation constructed solely in terms of 'authenticity' of representation, or which set up as two opposed approaches to participation those premised on empowerment and those based on consumerist consultation (e.g. Cook 2002), are fundamentally limited. Various authors have demonstrated the malleable nature of representation in the practice of public participation, emphasising the various (but not altogether negative) ways in which involved individuals draw on notions of 'the public' in negotiating public-involvement initiatives (Barnes *et al.* 2003; Contandriopoulos 2004). As Contandriopoulos (2004) points out, public-participation initiatives differ from conventional, narrowly democratically conceived forms of political action in that they usually do not rely for their legitimacy on the statistically-descriptively accurate representation of the public. However, his consequent conclusion, that the viability of a given public-participation mechanism therefore rests instead on claims to represent the public as a whole through a more symbolic construction of representation—"the political efficacy of public participation ultimately rests upon symbolic struggles to appropriate the intrinsic legitimacy of the public" (Contandriopoulos 2004: 328)—does not necessarily follow: there is more to these roles than representational claims, whether statistically or symbolically constructed. In short, the involved member of the public is more than just a token of the lay citizenry: rather, she embodies (and her legitimacy rests on) other qualities seen as important in governing the interface between state and society. This seems truer than ever with a contemporary social policy geared towards drawing productively on the attributes of certain groups of citizens in pursuit of effectiveness, whether those attributes are typicality, agency, reflexivity, communicative ability or whatever else.

There is some illustration of this trait of contemporary social policy in the wider literature (e.g. Schofield 2002; Green 2005), but as we see above, the public-involvement literature largely tends to understand and judge participation in terms of more traditional notions of representativeness, empowerment and to a degree, expertise. This arises, perhaps, from the fact that these criteria seem self-evident in the rationales for public participation: in different proportions, they are almost always cited in the justification for such initiatives. Looking below the surface, though, I suggest that these different aims coalesce in forms that transcend straightforward understandings of notions of 'democratic representation' or 'lay expertise'.

In the next section, I attempt to take this idea a little further by considering a specific example of recent policy in the UK on public involvement in health, and employing a discourse analysis to examine what rationales it invokes, and to what ends. Through this analysis, I seek to elucidate certain common features of the qualities required of involved members of the public, evident in the fog of overlapping and sometimes contradictory criteria for selection offered in these documents. The objects of my analysis are, firstly, the major policy documents produced by the UK Department of Health (DH) to provide instruction to managers and practitioners on what constitutes public participation and how involved publics should be selected and involved; secondly, documents produced by a support organisation, the Commission for Patient and Public Involvement in Health (CPPIH), which has overseen recent reforms in the mechanisms for public involvement in the National Health Service (NHS) in England, providing instruction to involved individuals about their role and responsibilities; and thirdly, publicity material produced by this body about opportunities to participate, designed to attract potential 'involvees'. My focus is on the rhetoric and results of the recent major overhaul of the system of public involvement in health in England instigated by the Labour government (described in more detail below), which came into effect from early 2003. As such, my analysis is largely limited to national-level policy and practice guidance documents and publicity materials produced from this time forward, plus policy documents produced prior to this which contributed to the reforms. It

does not therefore consider the plethora of locally commissioned and produced guidance on public involvement in health which emerged in the 1990s in response to the implementation of the 1990 NHS and Community Care Act, with its mandate for public involvement in commissioning decisions in health and social care (DH 1992).

Each of the bodies of literature considered offers an idea of what public involvement is about, and represents an attempt to structure its operation along these lines, for example through what it has to say on who should be participating and how. It is these assumptions and discursive functions that I seek to analyse here. Having selected all relevant material available by the 'author-organisations' (by performing keyword searches for terms such as 'public', 'involvement' and 'participation' on the DH website and downloading material from the relevant areas of the CPPIH's archival website), I read this through carefully, noting for subsequent analysis points at which the characteristics of the publics to be involved, the nature of their role, or the mechanisms by which they might be selected, were considered, and then considered these data together in terms of the ideas put forward (representativeness, knowledge, experience, background and so on) and the aims of the documents. In analysing this material, I pay close attention to the ideas about public participation articulated, including discrepancies and inconsistencies between and within documents, considering also the implied audiences of the different documents (practitioners and managers, involved members of the public, the public at large) and the rhetorical devices used in the discourses invoked.

Some 22 documents produced by central government (principally the DH) were analysed, primarily policy documents, but also circulars and press releases, while 25 documents from the CPPIH were considered, including internal policy guidance to staff and forum members and publicity materials such as brochures, leaflets and press advertisements.

Contemporary British participation policy

The system of Patient and Public Involvement (PPI) in health introduced by the British Labour government in the early 2000s has been described as an attempt to reconcile consumerism and citizenship in the lay accountability of the health service, putting right the failings of the overtly consumerist approach to involvement associated with internal-market legislation of the 1990s Conservative administration (Baggott 2005). Certainly, the reforms were radical, obliging NHS organisations to involve patients and the public in planning and changing services (Health and Social Care Act 2001), and abolishing the principal existing mechanisms for lay involvement since the 1970s, community health councils (CHCs), passing on their responsibilities to various new bodies (NHS Reform and Health Care Professions Act 2002). Among these bodies were PPI Forums, one for each NHS trust and Primary Care Trust (PCT), charged with the duty of monitoring services and ensuring that patients' and the public's views were included in planning and provision, with powers to inspect NHS premises and demand information. A support and performance-management body, the CPPIH, was set up, and subsequently scheduled for abolition (in 2006); plans were also initiated to rationalise PPI Forums to correspond only to commissioning PCTs.

Challenges to the pre-eminence in public involvement of CHCs had already emerged in the 1990s, in particular, as noted above, with the advent of the 1990 NHS and Community Care Act, and its emphasis on needs-led provision and consultation with the public (as consumers) on priorities and provision (DH 1992). In other fields such as urban renewal, area-based initiatives introduced by the then Conservative government were starting to emphasise the need for cross-sectoral solutions to 'vicious' problems, enfranchising diverse stakeholders including, in many cases, 'service users', 'the public' and 'communities'. This theme was enthusiastically adopted and deepened by the incoming Labour government in 1997, with its core preoccupation with partnership, collaboration and involvement in its Third Way approach to social policy. Inclusive, boundary-spanning area-based schemes such as the Single Regeneration Budget were extended and complemented by new ones, such as Education and Health Action Zones and Local Strategic

Partnerships, in which the network orientation which characterised much 'early-New' Labour ideology sought to break down barriers not only between professions and agencies but also with the public.

At around the same time, the report of the inquiry into the mismanagement of paediatric cardiac surgery at Bristol Royal Infirmary emphasised the role of *direct* involvement of *wideranging* groups of patients and publics in ensuring openness, safety and quality in healthcare, endorsing involvement "embedded in the structures of the NHS" to "permeate all aspects of healthcare" (Bristol Royal Infirmary Inquiry 2001: 409). The place of CHCs, as public-involvement bodies located outside the health service and with limited clout within it, was looking increasingly anachronistic. Concurrently, broader structural changes to the NHS—the so-called 'Shifting the Balance of Power' reforms which saw the creation of primary care groups (PCGs) and PCTs in the hope of creating a primary-care-led health service—were being instigated, with further consequences for the mechanisms of public involvement. With these supposed networks of primary-care professionals now responsible for commissioning patient care, there was clearly a case for the closer involvement of the public in the process. The legislation which transformed public-involvement processes followed soon afterwards, and DH press releases from this five-year period from inception to completion indicate the extent to which they were informed by calls for integration and partnership to empower involved publics, and inspired by New Labour ideology more generally, throughout the tenure of various health ministers:

We need to ensure that front-line staff have the right basic tools to make genuine patient and public involvement a reality. (John Denham (Health Minister), PR1999/0653)

[PPI Forums] will give citizens a real stake in their own local health services by ensuring that the voices of local people are heard by GPs and trusts who will control 75% of the NHS budget and have the power to instigate real change at a local level. (Hazel Blears (Health Minister), PR2001/0552)

The creation of the [CPPIH] signals a key shift in the balance of power of the NHS, ensuring national standards are controlled locally, giving the public real influence and power to modernise their NHS. (David Lammy (Health Minister), PR2003/0043)

When PPI Forums were first mooted (as Patients' Forums) in the NHS Plan (Secretary of State for Health 2000), various rationales for involvement were invoked. Forums were to be made up through the random selection of patients who had responded to the trust's annual survey, and through selection of representatives from local voluntary organisations, in equal proportions; subsequently, representation of the wider public (beyond patients) was added, and selection was replaced with application and appointment. Policy guidance offers various justifications for PPI, emphasising in particular three fundamental objectives: "strengthened accountability to local communities; a health service that responds to patients and carers; and a sense of ownership and trust" (DH 2003a: iii). There is stress on both accountability and the need to "tap into the enthusiasm and energy of ... patients, the public and local communities" (DH 2003a: 2).

Technocratic and democratic rationales are similarly emphasised in parallel guidance for practitioners, but in sometimes confused or contradictory ways. At one point, for example, this guidance plays down the need for representativeness, answering the claim that "patients and members of the public who do get involved are often unrepresentative" by responding:

Unrepresentative of who or what? Patients and members of the public bring their own experiences to the debate. Unless they are speaking on behalf of a patient's group or an established forum they are rarely able to represent the collective views of others. (DH 2003b: 50)

The variety of contributions beyond representational 'accuracy' are stressed, including "knowledge, experience of ... using services, behaviour, wants, information needs, attitudes, and considered and informed opinions" (DH 2003b: 39). Elsewhere, however, the document

specifically asks practitioners to ensure that “a representative cross-section of people, community groups and key stakeholders have been involved from an early stage” (DH 2003b: xii). Similarly, on the rare occasions when specific advice is given on exactly how NHS organisations should involve their publics, the issues raised are sometimes muddled. Practitioners are told to be clear about the area or subject that you are inviting patients and/or the public to be involved in. For example, the views of patients about primary care services are very wide, but the information needs of women with breast cancer are narrower and more manageable. Is the work aimed to give and/or receive information or do you intend to get more people involved? (DH 2003b: 31)

In urging reflection on the aims of involvement, then, the guidance apparently conflates the breadth or narrowness of the population being involved with the depth or shallowness of the issues being considered.

There is also a certain lack of clarity about the roles of PPI Forums and of local-government ‘Overview and Scrutiny Committees’ (OSCs), introduced in Labour’s reforms to subject the NHS to formal local democratic influence. Exhorted to interact and co-operate by guidance (DH 2003c), their remits overlap considerably. The language used in the practitioners’ guidance goes some way towards illuminating the marginal distinction between their rationales: where the role of PPI Forums is “to monitor and review NHS services of their trust from the patient’s perspective” and “inspect premises used by NHS patients from the perspective of the patient’s experience” (DH 2003b: 125), OSCs are to focus on “the planning, provision and operation of health services” (DH 2003b: 127), with an ability to summon, question and call to account trust chief executives. The emphasis on the place of *experience* and the view from a locatable *perspective*—that of the patient and member of the public—in the role of PPI Forums contrasts, perhaps, with the more objective concerns of the formal democratic remit of OSCs. If the function of PPI Forums is a representative one, then it is one imbued with experience, affectedness and other personal attributes rather than one where electorally or statistically accurate representation is most important.

Beyond experiential representativeness or experiential expertise, however, Forum members are expected to embody various other characteristics too. For a start, they are not there only to put their own views (representative or expert or not) to the trusts they partner; they must also seek out the experiences, needs and wishes of the wider patient and public population:

[PPI Forums] will be made up of local people and will represent the views of communities about the quality and configuration of health services to PCTs and trusts. This representation will be actively finding out what patients, carers and families think about their health services. (DH 2003b: 125)

The handbook issued to PPI Forum members offers advice about how to go about this task, stressing the need to consider “the experiences and needs of people living across the whole of your forum area,” including “differences between the health needs of one part of your area and the others,” any “particular health problems in your area,” and “communities whose opinions are overlooked” (CPPIH 2004a: 25). Direction about when and how to survey patients and the public follows. In terms of the commitment of time and level of competence required to carry out such activities effectively, what is needed here sounds more like the professional expertise of a public-health department than a ‘lay expertise’ of the kind examined above. The handbook acknowledges that PPI Forums will have to prioritise and be pragmatic, but even then the range of managerial, research and negotiation skills demanded is impressive. CPPIH staff are instructed to ensure that only “people with sufficient time and interest in health get the limited number of places available on the Forums” by selecting applicants on the basis of various criteria, including “understanding of the health needs of the community,” being “enthusiastic about making a difference,” and possessing the ability “to work as part of a team” (CPPIH 2003). In other documents, however, the emphasis of the CPPIH is on representativeness and diversity of background, seeking to stress in a progress report that Forum members are not just a select

clique:

10% of Forum Members were from ethnic minorities, as well as equal splits of 1/3 having never volunteered previously, 1/3 having volunteered before but not in health and the final 1/3 as having volunteered in health in the past. The Commission remains committed to help make Forums as representative of the communities they serve as possible. (CPPIH 2004b: 4)

Varied and impressive qualities are demanded, then, of Forum members and others involved in participation initiatives in health. Representativeness is required with experience and 'lay expertise', alongside various skills that one might associate with professional management—or at least with a highly developed reflexivity. Audit work carried out by the CPPIH's recruitment working group finds the extent to which these requirements are met in individual Forums to be variable: "some forums are very exclusive in that all members share the same demographic characteristics." This is seen by the working group as disadvantageous not only in terms of representativeness, but also skill mix, and the recommendation from the group is that such Forums create "a profile for the people currently on the forum to identify gaps of expertise." But whether or not participants fulfil these criteria in practice—indeed whether or not it is possible for them to fulfil all these criteria simultaneously—the fact that they are sought in the first place tells us something about what health policy wants from participation. From amidst the confusion within the policy literature emerges the kind of multifaceted ideal-type individual sought by the state.

The publicity materials used by the CPPIH to recruit to PPI Forums are particularly illuminating here, exhibiting the tension between the searches for representatives, 'lay experts', skilled reflexive citizens, and anyone to fill the requisite number of places decreed by statute.³ One early leaflet praises the amazing lengths to which people go to improve health—running marathons dressed as chickens, for example—before introducing PPI Forums as a new way of making an impact. Then the rejoinder: "ordinary people only—experts and chickens need not apply" (figure 1). Another, later, leaflet, however, explicitly suggests that "if you have knowledge or experience of a particular aspect of health or healthcare, you may wish to contact your Forum to contribute to discussions that may be taking place around that topic" (figure 2). A passage repeated on several leaflets affirms that "you may be young or old or from *any* section of the community—most importantly you'll want to check and challenge when it comes to health." Leaflets and advertisements stress the virtuous enthusiasm and local orientation of Forum members—"groups of volunteers in your local community who are enthusiastic about helping patients and members of the public influence the way that local healthcare is organised"—and implore their readers to make a similar commitment: "How many of us care enough to make a difference? Care enough to give a voice to patients? Care enough to give time and energy for health?"

Perhaps the strange mix of representativeness, diversity, ordinariness, knowledge and expertise to which these materials appeal to is best summed up in a passage repeated in several CPPIH leaflets:

Forum members will be champions for health and make the views of patients and the public heard.

That's why we need people like you—people who know their communities and will give their time to make a real difference.

Can you help to bring better health to your community?

3 Many of the materials discussed in this section are archived by the CPPIH and available to the public at

http://147.29.80.160/portal/topics/1081161438490_Resources?paf_dm=full&paf_gear_id=13300047&page_13300047=list_genericContentGear.jsp&topic_id=13400021.



People often do amazing things for health - running a marathon in a superchicken suit for one!

Now there's another way to make an impact by joining your new local forum for health.

Ordinary people only - experts and chickens need not apply.

make time for health

Patient and Public Involvement (PPI) Forum members will be champions for health and make the views of patients and the public heard.

That's why we need people like you - people who know their communities and will give their time to make a real difference.

Can you help to bring better health to your community?

Please call 0845 120 7115 or visit www.maketimeforhealth.org for more information and an application pack.

Or write to
Make Time for Health
 PO Box 11442
 Birmingham
 B2 4WP

General enquiries 0845 120 7111

PPI Forum Membership Recruitment Line
0845 120 7115

Lines are open
 8am to 10pm Monday to Friday
 9am to 5pm Saturday and Sunday
 Minicom 0845 120 7113

Commission for Patient and Public Involvement in Health

make time for health

**Care about health?
 Apply now -
 no fancy dress required**

Commission for Patient and Public Involvement in Health

Figure 1: Ordinariness as qualification for participation

What is required, above all, is this mystical quality of knowing one's 'community'—which is something, apparently, which people like *you* possess! You are ordinary enough, motivated enough and knowledgeable enough to take on the duties of a PPI Forum member—but of course *you* could be anyone who has picked up (and, perhaps crucially, read) a leaflet while attending a local health service. The materials appeal to "local people," "ordinary people", "people who know their communities," seeking to link personal concern with individual health to a common communitarian consciousness that demands collective responsibility and collective action.

'Ordinariness' and commonality with the 'wider community' have a special place in these appeals: not only do they provide particular insights unavailable through other mechanisms, but they also enhance the ability of Forum members to perform their role of accessing the local population to uncover its views and needs in ways that public-health research, apparently, cannot. The practitioners' guidance endorses as good practice an example of this kind of capacity, relating the work of one PCG which (prior to the PPI reforms) employed older people as 'peer researchers' in a survey of older people:

The PCG advertised for older people to undertake the interviews through older people's groups and the media. It trained seven volunteers who undertook the interviews in people's homes. This allowed the PCG to reach 'the hard reach' [sic] people in the borough, use the skills of older people to build a comprehensive picture of the needs of the local people, and obtain a frank and realistic view of the issues. (DH 2003b: 61)

Commonality, experience and various talents, including drive and enthusiasm, come together in the kind of mediating role of participation that makes the population knowable to the health service in ways not achievable through the state's traditional means.

How can I get involved?

Everyone, from all parts of the community, is encouraged to get involved with their local PPI Forum to ensure that their voice is heard.

Your local Forum will have regular meetings in public and you are welcome to attend these, perhaps to voice any concerns or issues you might have around health and healthcare in your area. If you have knowledge or experience of a particular aspect of health or healthcare, you may wish to contact your Forum to contribute to discussions that may be taking place around that topic.

Alternatively, you may wish to apply to join a PPI Forum as a volunteer.

How do I contact my local Forum?

If you have any concerns or issues that you would like to raise with a PPI Forum or if you are interested in attending one of their meetings in public, please contact:


Commission for Patient and Public Involvement in Health

Tel: 0845 120 7111
E-mail: enquiries@cppih.org
www.cppih.org

For more general information about PPI Forums please contact:

Commission for Patient and Public Involvement in Health

Tel: 0845 120 7111
Fax: 0121 222 4511
Minicom: 0845 120 7113
E-mail: enquiries@cppih.org



Patient and Public Involvement Forums



Commission for Patient and Public Involvement in Health



66 The PPI Forums are an opportunity to get a stronger voice for everyone, but I believe it is particularly important for areas of society who may have previously felt their views have gone unheard. **69**

Charlie, Forum Member, Sheffield

Commission for Patient and Public Involvement in Health

Figure 2: Expertise as qualification for participation

Discussion and conclusion

In this analysis I have attempted to show that while the new system of PPI in England draws on discourses of both expertise and representation, the way in which it does so transcends democratic and technocratic rationales. Whilst this is only a discourse analysis, and therefore has a limited amount to say on the material reality of Forum members and other involved members of the public, it is clear that the requirements of those individuals have been a major concern for the CPPIH. It has monitored the composition of Forums from the start, and although figures on this are not publicly available, the importance of these to the CPPIH is evident from its update materials, which emphasise the success of Forums in attracting a balanced and representative membership and reaffirm the Commission's commitment to diversity and representativeness, and its internal policy documents, which highlight deficiencies in the membership of Forums and suggest remedies to this which by improving representational accuracy might also improve the skill mix.

It is more difficult by way of an analysis of this kind to demonstrate the material outcomes of these policy intentions, though it is worth noting that more recent Department of Health guidance on Local Involvement Networks (LiNs), which will supersede PPI Forums, proclaims the success—in parts of the country—of involving “local people—young and old—[...] in planning, developing and making decisions about health and social care services,” and states an intention to build on and deepen these achievements through the new arrangements (DH, 2006).⁴

4 With a view to joining up public-participation efforts across sectors and transcending the divide between health and social-care provision, these bodies will be hosted by local government. Thus those who will be responsible for developing and managing LiNs have an established

Elsewhere, similar ‘person specifications’ are evident in other regulatory mechanisms in health, such as the National Institute for Health and Clinical Excellence, which requires lay members of its committees and working groups to have “experience of health services and the issues that are important to people with the condition(s) or subject area(s) covered,” including, in the case of its public-health committees, experience that “could include active work in the community to promote public health or to prevent illness.”⁵ The Medical Research Council’s advisory group on public involvement is composed of “members drawn from all walks of life, [who] share an interest in health and research”;⁶ an expert advisory committee to the DH on new and emerging infections calls for lay members who “have and understanding of the issues associated with public health and communicable disease” and who “have experience of committee work.”⁷ There is also, though, an interesting contrast with the kinds of citizens targeted by recent efforts at public participation in bioscience policy (e.g. Irwin 2001, 2006) which sought to bypass ‘active citizens’ in pursuit of a more inert, supposedly more representative ‘reactive’ public. This serves to highlight, perhaps, “the practical significance of the *institutional location* of public consultation exercises” (Irwin 2001: 13): where the initiatives Irwin studied were set up primarily as tools by which civil servants could gauge public opinion to guide future policy-making, these new arrangements for public involvement in the NHS are, as we have seen, explicitly intended to break down the barriers between involvement and the management and delivery of services, requiring a more formative, bidirectional and ‘active-citizen-led’ process, using involved individuals who are insiders both of the health service and of the various communities and publics being targeted.

As argued earlier in the paper, then, any discussion of public participation which limits its analysis to the extent of empowerment, the accuracy of representation or the expertise of those involved neglects the most crucial dimensions of contemporary public-participation policy. Although the contradictions and overlaps might simply be seen as exemplifying confusion and ambiguity in policy discourse and implementation, what I hope I have demonstrated is that a coherent, if multifaceted, picture emerges from these official documents of who this involved public should be and how they should operate. Contrary, then, to Baggott’s (2005: 547) argument that “the relationship between PPI forums and their constituencies appears weak and this is partly because little thought has been given to the nature of their representative function,” PPI must be considered in terms of the range of pragmatic and productive connections it engenders. The ideal involved members of the public, as demanded by PPI, are hugely multifaceted individuals, but what seems to be asked above all is that they know and can make knowable their constituencies. Partly, this is by virtue of their typicality and commonality. But it is also to be achieved through their labour, their efforts to understand better the views of local populations, something which is aided by the combination of their ordinariness—their very laity—and their extraordinary enthusiasm and armoury of reflexive skills.

What emerges is a conception of the involved member of the public as filling a mediating role of the kind identified in certain other areas of contemporary social policy in economically developed countries (Petersen 1997, Schofield 2002, Green 2005): lay individuals whose disposition and social location provide particularly acute insights to government. Such insights make knowable the vagaries of the wider population which involved individuals articulate through typicality, commonality or communicative skill, and help to ensure the appropriateness and efficacy of public services to that population. They are almost, perhaps, ‘experts in laity’.

relationship of democratic accountability to local populations—perhaps with the potential to cloud further the nature of the representative function of these future bodies.

5 Source: <http://www.nice.org.uk/page.aspx?o=242614>, accessed 2 October 2006

6 Source: http://www.mrc.ac.uk/index/public-interest/public-advisory_group_public_involvement.htm, accessed 2 October 2006

7 Source: *Guardian*, 5 July 2006

There are echoes, here, of the mechanisms of government specified in Foucaultian accounts of advanced-liberal governmentality. These emphasise how contemporary government rests not on 'top-down' regulation, compulsion and direction by the state and its agencies, but on the rational actions and choices of the subjects of government, self-regulating citizens, following Foucault's (1981: 89) intimations about the operation of power "on all levels and in forms that go beyond the state and its apparatus." In this way society is governed "through the regulated choices of individual citizens, now constructed as subjects of choices and aspirations to self-actualization and self-fulfilment" (Rose 1996: 41). Even in this contemporary order of 'bottom-up' regulation-through-autonomy, however, there are certain loci of power through which the aims of the individual subject are aligned with those of government and through which governmental authority comes to know and understand its subjects, thereby achieving more effective techniques of government. Rose and Miller (1992) highlight the role of certain experts who act as intermediaries between governmental authority and the individual—doctors, teachers, other sources of knowledge—so that

by means of expertise, self regulatory techniques can be installed in citizens that will align their personal choice with the ends of government. The freedom and subjectivity of citizens can in such ways become an ally, and not a threat, to the orderly government of a polity and a society. (Rose and Miller 1992: 188-9)

Similarly, Rose (1993) conceptualises the quasi-market as a 'free market' in expertise, in which the regulatory function of rational citizens is assigned to commissioning organisations, experts in the needs and wishes of the public, while "experts of community" such as academic and market researchers are deployed to make knowable what 'the public' wants (Rose 1999: 189).

What we seem to be seeing in public involvement, and in these other related areas of contemporary Western social policy mentioned above, is a curious development in this mode of governmentality. Particular members of the public—archetypally 'active' citizens, with productive subjective qualities varying from willingness to rationality to knowledge of their peers—seem to be cast in new interpretations of these crucial mediating roles of governmentality. They bring together experience, representativeness and knowledge in new configurations as considered above, which help to make knowable the wills and whims of the governed to governmental power: the crucial input upon which a modernised welfare state, fashioned around the idea of a fundamentally changed, reflexive society, rests for its success. What we see, moreover, in the British policy context, is the way in which it is not just the background and features of these individuals, but their *labour*, too, which is crucial in this process of illumination. Their position is seen as offering a privileged vantage point for making understandable all sorts of peculiarities throughout society to the health service: for them, the needs and views of 'hard-to-reach groups', for example, are seen as less hard to reach. The knowledge gained from such exercises is then to feed into the priority-setting processes of the health service. This mediating role, then, is one which is as much about the government of the health service and its agents—including some of the traditional experts of governmentality—as the government of laypeople's conduct. Much of the governmentality-studies literature focuses on the mechanisms of new-right, neoliberal government. The example of these very recent developments in PPI policy discourse in England (tied, as we have seen, closely to wider Third Way policy in the NHS and beyond) suggests, perhaps, some of the ways in which advanced-liberal technologies of government have evolved in a policy context which emphasises the merits of partnership, integration and networks between communities, private organisations and the state, alongside quasi-marketisation and top-down accountability.

There are of course dangers associated with public-participation policy constructed in this way. The marginalisation of conventional democratic mechanisms of accountability and governance may result in state provision that neglects 'reflexivity losers' and those who fall short of the 'active citizen' ideal (Clarke 2005, cf. Ellison 1997, Petersen 1997), or which prioritises the soothing of individual concerns of truncated consumer-citizens ahead of questions of the

collective interest (Chandler 2001). However, there is potential, too, and the key question is about the operation of public-participation initiatives in practice. What this kind of analysis cannot show is how public participation is played out through the agency of those involved in it as professionals and 'involvees'; as Contandriopoulos (2004) contends, normative expectations of how the public should be represented are unhelpful in this regard. If, then, conceptualising public involvement in terms of how far it conforms with democratic or technocratic ideals is a futile pursuit, then focus needs to move to how in practice these and other rationales are put to discursive effect, how individuals' characteristics develop through the involvement process, and with what material consequences for those involved and not involved in public-participation processes.

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